DOCUMENT RESUME

ED 217 617 EC 142 500

TITLE Special Report on the Impact of the Change in the Definition of Developmental Disabilities (Mandated in P.L. 95-602, Sec. 502(b) (2)).
INSTITUTION Office of Human Development Services (DHHS), Washington, D.C.
PUB DATE May 81
NOTE 77p.

EDRS PRICE MF01/PC04 Plus Postage.
DESCRIPTORS Compliance (Legal); *Definitions; *Delivery Systems; *Developmental Disabilities; *Federal Legislation; Federal Programs; *Human Services; Incidence; *Trend Analysis
IDENTIFIERS *Developmental Disabled Assist Bill of Rights Act

ABSTRACT

The report analyzes the impact of the change from a categorical definition of developmental disabilities to one which emphasizes functional limitations and the accompanying need for services as mandated by the 1978 Developmental Disabilities Assistance and Bill of Rights Act (P.L. 95-602, Section 502). Part I is an introduction with sections on the purpose of the report, an overview of the Developmental Disabilities Program, current and previous definitions of developmental disabilities, reasons for change in the definition, summary of key findings on the developmentally disabled population in the United States, resource documents, and organization of the report. Part II summarizes data on the effect of the definitional change and presents information on the impact of the change in each of the four components of the Developmental Disabilities Program: Basic Grant Program, which provides grants for planning, coordination, and systems advocacy; Protection and Advocacy System, which provides grants to protect and advocate for the rights of developmentally disabled individuals; University Affiliated Facilities Program, which provides grants for administrative and operational costs related to the training and research programs conducted by the facilities; and Special Projects, which provides grants to demonstrate improved methods of service delivery and protection and advocacy services. A final section lists 11 conclusions including that the study did not reveal any causal relationships between the quality assurance efforts and the change in the definition. Appendixes contain a report on the historical evolution of the definition of developmental disabilities, a summary of key findings on the developmentally disabled population, an annotated list of primary resource documents, and a table of statistics estimating the developmentally disabled population. (SB)

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# SPECIAL REPORT ON THE IMPACT OF THE CHANGE IN THE DEFINITION OF DEVELOPMENTAL DISABILITIES

(MANDATED IN P.L. 95-602, SEC. 502(b)(2))

U.S. Department of Health and Human Services
Office of Human Development Services
Administration on Developmental Disabilities
Washington, D.C.
May 1981

ED217617

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## Executive Summary

The 1978 Developmental Disabilities Assistance and Bill of Rights Act mandated that the Secretary submit to the Congress a special report on the impact of the change from a categorical definition of developmental disabilities to one which emphasizes functional limitations and the accompanying need for services. The Act calls for a report which analyzes the impact of the change in terms of the numbers of individuals served, the funds expended, and the quality of the services provided before and after passage of the 1978 law.

The findings of several definition related efforts were analyzed to develop the Secretary's report. The following observations were made of the data available to address the concerns expressed in the Act:

### Individuals Planned for

- There has been a 27% decrease in the estimated total developmental disabilities population, as defined in the 1978 amendments, based on an analysis of the 1980 Developmental Disabilities State Plans. Whereas in FY 1978 the estimated number of individuals defined as developmentally disabled in the United States was 5,265,846, in FY 1980 the estimated figure was 3,906,913.

- The application of the functional definition seems to have resulted in the identification of more substantially handicapped individuals as developmentally disabled.

- Mental retardation in FY 1980 represented 54.8% of those defined as developmentally disabled, compared with 65.5% in FY 1978. During the

same time period, the estimated number of individuals considered developmentally disabled with cerebral palsy increased, with epilepsy decreased, and with autism remained essentially the same. In addition, individuals with other conditions who are now included within the developmentally disabled target population currently account for almost 12% of the population.

- There continue to be differences in the population considered to be developmentally disabled. Although the total population estimated in the State plans was almost 4 million developmentally disabled individuals, a study utilizing the developmentally disabilities definition in conjunction with the 1976 Survey of Income and Education estimated 2.5 million developmentally disabled individuals.

Individuals Served

- In the Protection and Advocacy System, the number of mentally retarded individuals served has decreased and the number of individuals served with other disabling conditions has increased.

- In the University Affiliated Facilities (UAF) Program, the percentage served in each category of condition has remained stable for the three years.

Expenditures

- Mental retardation remains the condition for which over half of the expenditures in each component in FY 1978 and FY 1980 were made; however, there was a 6% decrease in expenditures for mental retardation in the four program components between FY 1978 and FY 1980. The

reduction in the mental retardation expenditures can be related to the focus on substantiality in the functional definition. Generally, mildly mentally retarded individuals are no longer included in the developmentally disabled population unless they have multiple handicaps which in combination substantially limit their ability to function.

- Expenditures in the category cerebral palsy increased approximately 44% between FY 1978 and FY 1980, epilepsy decreased 16%, autism increased 17% and expenditures for conditions other than the four mentioned in the 1975 law quadrupled.

Quality Assessment

- Although the intensity of quality related activities has increased in the years following the enactment of P.L. 95-602, few of these activities can be related directly to the change in the definition of developmental disabilities.

## PART I: INTRODUCTION

### Purpose of the Report

The purpose of this special report is to inform the Congress of the impact of the functional definition of developmental disabilities incorporated into the Developmental Disabilities Assistance and Bill of Rights Act in 1978. The 1978 Amendments, contained in Public Law 95-602, specified that the Secretary submit a special report to the Congress on the impact of the newly enacted functional definition:

> Sec. 502(b)(2) The Secretary of Health, Education and Welfare shall submit to Congress not later than January 15, 1981, a special report concerning the impact of the amendment of the definition of "developmentally disabled" made by paragraph (1). This report shall include—
>
> (A) an analysis of the impact of the amendment on each of the categories of persons with developmental disabilities receiving services under the Developmental Disabilities Assistance and Bill of Rights Act before the date of enactment of this Act, and for the fiscal year ending on September 30, 1979 and for the succeeding fiscal year, including—
>
> (i) the number of persons with developmental disabilities in each category served before and after such date of enactment; and
>
> (ii) the amounts expended under such Act for each such category of persons with developmental disabilities before and after such date of enactment; and
>
> (B) an assessment, evaluation and comparison of services provided to persons with developmental disabilities provided before the date of enactment of this Act and for the fiscal year ending September 30, 1979 and for the succeeding fiscal year.

Overview of the Developmental Disabilities Program

The purpose of the Developmental Disabilities Program is to improve and coordinate the provision of services to persons with developmental disabilities, those severe and chronic disabilities which result in substantial functional limitations in the major activities of daily living.

The basic goal of the program is to provide for significant improvement in the quality, scope and extent of services for persons with developmental disabilities by means of:

- Comprehensive planning for current and future service needs, including needs and resource assessment, analysis of resources against needs, and prioritizing objectives and unmet needs;
- Coordination and appropriate integrated utilization of services and resources at all levels of government and the private sector for more effective utilization of existing resources for developmentally disabled persons; and
- Demonstration of new programs designed to fill existing gaps in specialized services.

The developmentally disabled persons to be served comprise about 9 percent of the twenty-nine million physically and mentally disabled in the country. Their disabilities are chronic and severe, with many having multiple handicaps due to other impairments and disorders such as blindness, deafness, absence of language, orthopedic defects and emotional disturbance. About 150,000 reside in State public institutions for the mentally retarded. About 2.5 million, over age three, are non-institutionalized and reside either with their families or in supervised alternative community-based living arrangements.

The aim of the program is to move the developmentally disabled individual from total dependency to his or her maximum level of independent functioning. This can be accomplished through the provision of a combination of specialized or generic services which are individually planned and delivered under the separate jurisdiction of a variety of service agencies all relying primarily or exclusively on States.

To accomplish these purposes, the Developmental Disabilities Program has four major program components:

- Basic State Grant Program, which provides grants to States for planning, coordination, and systems advocacy;
- Protection and Advocacy System, which provides grants to States to protect and advocate for the rights of developmentally disabled individuals;

- University Affiliated Facilities Program, which provides grants for administrative and operational costs related to the training and research programs conducted by the facilities; and
- Special Projects, which provide grants to public and non-profit organizations to demonstrate improved methods of service delivery and protection and advocacy services.

More specific information on each of these program components will be presented in Part II of this report.

The Current and Previous Definitions of Developmental Disabilities

The current definition of developmental disabilities, as contained in Public Law 95-602, the "Developmental Disabilities Assistance and Bill of Rights Act", Section 102(7), is:

> "(7) The term 'developmental disability' means a severe, chronic disability of a person which—
> (A) is attributable to a mental or physical impairment or combination of mental and physical impairments;
> (B) is manifested before the person attains the age twenty-two;
> (C) is likely to continue indefinitely;
> (D) results in substantial functional limitations in three or more of the following areas of major life activity: (i) self-care, (ii) receptive and expressive language, (iii) learning, (iv) mobility, (v) self-direction, (vi) capacity for independent living, and (vii) economic sufficiency; and
> (E) reflects the person's need for a combination and sequence of special interdisciplinary, or generic care, treatment, or other services which are of life-long or extended duration and are individually planned and coordinated."

The definition of developmental disability contained in Public Law 95-602, sometimes referred to as the new definition of developmental disability, is based solely on an individual's functional limitations and need for services, rather than the diagnosis or nature of his or her disabling condition.

The previous definition of developmental disability contained in Section 102(a)(7) of Public Law 94-103, the one used by the Developmental Disabilities Program until November 1978, generally applied to persons with one of the four handicapping conditions listed:

The term "developmental disability" means a disability of a person which--

> "(A)(i) is attributable to mental retardation, cerebral palsy, epilepsy, or autism;
>
> "(ii) is attributable to any other condition of a person found to be closely related to mental retardation because such condition results in similar impairment of general intellectual functioning or adaptive behavior to that of mentally retarded persons or requires treatment and services similar to those required for such persons; or
>
> "(iii) is attributable to dyslexia resulting from a disability described in clause (i) or (ii) of this subparagraph;
>
> "(B) originates before such person attains age eighteen;
>
> "(C) has continued or can be expected to continue indefinitely; and
>
> "(D) constitutes a substantial handicap to such person's ability to function normally in society."

In addition, the conference report on the 1978 Amendments carried a provision the the functional definition was intended to cover everyone covered under the P.L. 94-103 categorical definition. The conferees stressed that individuals currently receiving services should continue to receive those services irrespective of the revised definition. Data are not available to assess the impact of this "hold harmless" provision on the Developmental Disabilities Program.

This report contains the analysis of the impact of the change in the definition of developmental disabilities, in terms of both the numbers of individuals served and the Federal expenditures before and after enactment of Public Law 95-602 and the assessment of services provided to individuals with developmental disabilities. The baseline for the data to be analyzed is fiscal year 1978, the last year that the categorical definition from Public Law 94-103 was in effect. The succeeding fiscal years, fiscal years 1979 and 1980, saw the introduction of a functional definition of developmental disabilities into the service network for individuals with developmental disabilities.

The basic assumption of the report is that the fiscal year 1978 funds were expended based on the categorical definition of developmental disabilities and that the fiscal year 1979 and fiscal year 1980 funds were expended based on the functional definition of developmental disabilities.

The mandate for this special study grew out of concern that the use of a functional definition of developmental disabilities could result in a diminution of services to individuals with the conditions specifically mentioned in Public Law 94-103. Part II of this report discusses the specific impact of the change in the definition.

Reasons for the Change in the Definition of Developmental Disabilities

The philosophy underlying the Developmental Disabilities Program is unique in its broad ecumenical approach to advocacy and planning for a target population with various disabilities and needs. Since the inception of the Developmental Disabilities Services and Facilities Construction Act of 1970, the Developmental Disabilities Program has attempted to bring together a variety of agencies traditionally serving disabled persons to develop a coordinated and comprehensive service delivery system for its target population.

Because of the unique broad-based approach to the program, it is not surprising that ambiguity has existed about the program's target population. The question of which groups of disabled persons fall under the term "developmentally disabled" and which groups do not qualify has been raised by various agencies, programs, and consumers.

A discussion of the historical evolution of the definition of developmental disabilities, beginning with the originating legislation (P. L. 88-164) and tracing it through the current law, is contained in Appendix A. The bases for the changes reflected in P. L. 95-602 are, as determined by the National Task Force on the Definition of Developmental Disabilities who conducted the independent study mandated in P.L. 94-103 :

- The need to focus scarce resources on that segment of the disabled population most in need of services;
- Developmentally disabled persons will require a combination and sequence of special interdisciplinary or generic care, treatment or other services which are of lifelong or extended duration and are individually planned and coordinated;
- The target population of developmentally disabled individuals is substantially and chronically disabled;
- Service agencies' traditional approaches are not oriented toward meeting the unique needs of this population so that the following combination is required:

  Comprehensive planning;

  Improved leverage on existing monies;

  Increased access to existing services;

  Interdisciplinary services in a variety of service delivery modes;

  Advocacy to ensure the above; and

  Coordination of services at the delivery point to ensure that needs are met.

- Concern that individuals with conditions or disabilities other than the four listed in P. L. 94-103 might share the limitations and service needs of the four named conditions and because of the definition be denied services.

The purpose of the functional definition was to emphasize the complexity, pervasiveness, and substantialty of the disabling conditions to be addressed by the Developmental Disabilities Program by focusing on the individual's functional limitations and the resulting need for comprehensive services. Thus, the definition of developmental disabilities changed from one which was categorically based to one which is functionally based.

Summary of Key Findings on the Developmentally Disabled Population in the United States

Included as an appendix to this report are the findings contained in the document entitled "Estimates of the Size and Characteristics of the Non-Institutionalized Developmentally Disabled Population in the United States Based Primarily on an Analysis of the 1976 Survey of Income and Education" which was prepared by Morgan Management Systems, Inc. and Gollay and Associates.

These findings were derived from an analysis of the Survey of Income and Education (SIE), conducted in 1976 by the U.S. Bureau of the Census on the non-institutionalized population over age three. Each of the criteria in the definition of developmental disabilities was operationalized for use with the data gathered. Since the SIE was not conducted with the

definition of developmental disabilities in mind, the operationalization of the criteria was not easy or precise. However, as can be seen from the summarized findings, the methodology used produced results generally consistent with other estimates; provides considerable additional insight into the characteristics of the developmentally disabled population; and, compares both non-developmentally disabled persons and non-disabled persons.

Resource Documents

The resource documents utilized by Departmental staff to develop this report are listed below. Each of these documents are described in Appendix C.

1. The Impact of the Amendment of the Definition of "Developmentally Disabled" on the DD Program in FY '79 and FY '80

2. A Study of the Potential Impact of the Definition Recommended by the National Task Force on the Definition of Developmental Disabilities

3. Secretary's Report to Congress on the Definition of Developmental Disabilities (1978)

4. Final Report of the Special Study on the Definition of Developmental Disabilities

## Organization of the Report

The main body of the report, Part II, summarizes data on the effect of the definitional change and presents information on the impact of the change in each of the four components of the Developmental Disabilities Program. The final section of the report discusses the conclusions and findings of the analysis of the data.

## PART II: COMPONENTS OF THE DEVELOPMENTAL DISABILITIES PROGRAM

The mandate for this special study requires an analysis of the impact of change in the definition of developmental disabilities, in terms of the number of individuals served, the Federal expenditures, and an assessment of the services provided before and after enactment of P. L. 95-602 in 1978. Since the concern is that individuals with any of the previously listed categories of conditions continue to receive services, the data are displayed with the four categories specified: mental retardation, cerebral palsy, epilepsy, and autism. The category "other" is used for those conditions which are now included as a result of the change to a functional definition, such as spina bifida, tuberous sclerosis, ostegenesis imperfecta, multiple sclerosis, or Tourette's syndrome.

The following sections present the appropriations for the Developmental Disabilities Program for each of the three years by program component, summary findings on the impact of the change in the definition in terms of the developmentally disabled population planned for or served, the expenditures, and the assessment of quality and then a discussion of the impact within each program component.

### Appropriation Levels for Program Components

Because the changes in funding levels which occurred between FY 1978-80 had some impact on each of the program components, it is necessary to examine these appropriation levels when assessing the impact in the change

of the definition. The following chart gives some perspective on the size of the total Developmental Disabilities Program and each of its components for the three fiscal years being analyzed:

| Program Component | Fiscal Year '78 Amount | % | Fiscal Year '79 Amount | % | Fiscal Year '80 Amount | % |
|---|---|---|---|---|---|---|
| Basic State Grants | $30,058 | 50.8 | $35,331 | 59.8 | $43,180 | 69.2 |
| Protection & Advocacy | 3,000 | 5.1 | 3,801 | 6.4 | 7,500 | 12.0 |
| Special Projects | 19,567 | 33.0 | 12,573 | 21.3 | 4,756 | 7.6 |
| University Affiliated Facilities | 6,500 | 11.1 | 7,420 | 12.5 | 7,000 | 11.2 |
| TOTAL | $59,125 | 100 | $59,125 | 100 | $62,436 | 100 |

(In thousands of dollars)

There was no increase in the appropriated funds from FY 1978 to FY 1979. In FY 1980 the amount appropriated for the program represented an increase of $3,311,000, or 5.6 percent increase over the FY 1979 level.

The Basic State Grants account for the major part of the program resources. In FY 1978 the $30 million represented just over 50 percent of program resources. In FY 1979 the amount for Basic State Grants was increased to just over $35 million without an increase of the total amount appropriated for the DD Program. The $35 million represented almost 60 percent of program resources. In FY 1980 the Basic

State Grants received just over $43 million and represented 69 percent of the program resources. Special project funds were used to augment the Basic State Grant Program.

In fiscal year 1978, the Protection and Advocacy Program was modestly funded at $3,000,000 with a minimum allotment State receiving only $20,000 to implement a statewide system of Protection and Advocacy. The $3 million represented only 5.1 percent of the total program budget. In fiscal year 1979 the allotment was increased to $3.8 million due to the fact that Public Law 95-602 required that each minimum allotment State receive no less than $50,000 for its system of Protection and Advocacy. In fiscal year 1980, the total allotment for Protection and Advocacy was $7.5 million and represented 12 percent of the total program budget.

In fiscal years 1979 and 1980, Special Project funds were used to increase the funds available for the Basic State Grant Program. Consequently, these funds represented only 21.3 percent and 7.6 percent of the total program funds for those two fiscal years compared with 33 percent of the total program allotment for fiscal year 1978.

Funding for the University Affiliated Facilities Program in fiscal year 1978 was $6.5 million, or 11 percent of the program resources. The University Affiliated Facilities received $7.4 million in fiscal year 1979, which represented 12 percent of the program resources. The amount appropriated in fiscal year 1980 was $7.0 million, or 11.2 percent of the program budget and a decrease of $400,000, or 5 percent, from the fiscal year 1979 level of funding.

It must be remembered, however, that the Developmental Disabilities Program appropriation of $62 million is only 1.5 percent of the total $4.4 billion expended annually by Federal programs which provide services to developmentally disabled individuals.

Summary of Information on the Developmental Disabilities Program

The observations which can be made from the summary data on the total program are presented below for each of the major areas of concern identified in the Congressional mandate for this study: individuals planned for or served, expenditures, and assessment of services provided. The relevant charts follow the summary observations.

1. Individuals Planned for or Served - Summary Observations

   - Individuals planned for under the Basic State Grant Program are those receiving services under the other three components (Protection and Advocacy, University Affiliated Facilities and Special Projects).
   - Increases or decreases in the total number served are more reflective of changes in funding levels than a change in the definition.
   - Both in terms of planning and service delivery, the number and percentage of "others" in each program component can be attributed to the change in the definition. It should be noted, however, that the number of "others" served in the UAF Program remained basically the same during the study time period.

- The more than double increase in "others" served in the Protection and Advocacy system can be attributed to the change in the definition as well as the fact that numerous State protection and advocacy offices are mandated by State law to serve all disabled. Although the funds from the Developmental Disabilities Program are used only on services to developmentally disabled individuals, the reporting systems may not distinguish the source of funding.
- Although the percentage of mentally retarded individuals served may have decreased in each of the components, the percentage component is still roughly equivalent to the 55 percent of the total developmental disabilities population represented by the mentally retarded.

2. Amounts Expended - Summary Observations

- The amounts expended for each condition increased from FY 1978 to FY 1980 although the percentage of the total may have decreased.
- Mental retardation remains the condition on which over half of the expenditures in each component in FY 1978 and FY 1980 were made.

- There was a 6 percent decrease in expenditures for mental retardation in the four program components between FY 1978 and FY 1980.
- The reduction in the mental retardation expenditures can be related to the focus on severity of the condition in the functional definition. Generally, the mildly mentally retarded are no longer included in the developmentally disabled population unless there are multiple handicaps which in combination substantially limit the individual's ability to function.
- Expenditures in the category cerebral palsy increased approximately 44 percent between FY 1978 and FY 1980. There seems to be no clear explanation for this change at this time.
- There was a 16 percent decrease in expenditures for the epilepsy category between FY 1978 and FY 1980. The epilepsy groups had been concerned when the functional definition was enacted that those individuals with epilepsy whose seizures could be controlled with drugs so that their limitations were minimal would no longer be defined as developmentally disabled.
- Expenditures for autism increased approximately 17 percent between FY 1978 and FY 1980. The study did not reveal causal factors for this change.

- The category "other" increased by 400 percent. The expenditures in this category quadrupled between FY 1978 and FY 1980. This is attributable to the change in the definition.

## Individuals Planned for or Served [1]

### Summary

| | Fiscal Year 1978 | | Fiscal Year 1979 | | Fiscal Year 1980 | |
|---|---|---|---|---|---|---|
| **Basic State Grants** | | | | | | |
| Mental Retardation | 3,518,742 | 65.5 | 3,291,862 | 64.3 | 2,140,988 | 54.8 |
| Cerebral Palsy | 505,269 | 9.4 | 623,909 | 12.2 | 558,688 | 14.3 |
| Epilepsy | 1,064,479 | 21.8 | 1,007,646 | 19.7 | 679,802 | 17.4 |
| Autism | 79,866 | 1.5 | 75,431 | 1.5 | 62,510 | 1.6 |
| Other | 97,490 | 1.8 | 120,011 | 2.3 | 464,925 | 11.9 |
| TOTAL | 5,265,846 | 100 | 5,118,859 | 100 | 3,906,913 | 100 |
| **Protection and Advocacy** | | | | | | |
| Mental Retardation | 9,542 | 65.8 | 16,265 | 60.2 | 14,073 | 51.6 |
| Cerebral Palsy | 1,218 | 8.4 | 1,756 | 6.5 | 2,236 | 8.2 |
| Epilepsy | 1,377 | 9.5 | 1,513 | 5.6 | 2,209 | 8.1 |
| Autism | 464 | 3.2 | 865 | 3.2 | 927 | 3.4 |
| Other | 1,900 | 13.1 | 6,619 | 24.5 | 7,828 | 28.7 |
| TOTAL | 14,501 | 100 | 27,018 | 100 | 27,273 | 100 |
| **Special Projects** | | | | | | |
| (Information not available) | | | | | | |
| **University Affiliated Facilities** | | | | | | |
| Mental Retardation | 12,455 | 55.0 | 12,924 | 55.0 | 13,475 | 55.0 |
| Cerebral Palsy | 1,902 | 8.4 | 1,880 | 8.0 | 2,009 | 8.2 |
| Epilepsy | 1,450 | 6.4 | 1,316 | 5.6 | 1,470 | 6.0 |
| Autism | 725 | 3.2 | 752 | 3.2 | 833 | 3.4 |
| Other | 6,114 | 27.0 | 6,627 | 28.2 | 6,713 | 27.4 |
| TOTAL | 22,646 | 100 | 23,499 | 100 | 24,500 | 100 |

1 The figures for the Basic State Grant Program cover individuals planned for while the figures for the other components cover individuals served.

## Expenditures

## Summary

| | Fiscal Year 1978 | | Fiscal Year 1979 | | Fiscal Year 1980 | |
|---|---|---|---|---|---|---|
| **Basic State Grants** | | | | | | |
| Mental Retardation | $21,290,812 | 70.8 | $23,877,602 | 67.6 | $26,363,863 | 61.1 |
| Cerebral Palsy | 2,673,606 | 8.9 | 4,389,011 | 12.4 | 5,283,336 | 12.2 |
| Epilepsy | 4,646,130 | 15.5 | 4,385,125 | 12.4 | 5,109,232 | 11.8 |
| Autism | 957,024 | 3.2 | 1,217,963 | 3.4 | 1,339,173 | 3.1 |
| Other | 490,428 | 1.6 | 1,461,299 | 4.2 | 5,084,396 | 11.8 |
| TOTAL | 30,058,000 | 100 | 35,331,000 | 100 | 43,180,000 | 100 |
| **Protection and Advocacy** | | | | | | |
| Mental Retardation | 2,119,102 | 65.8 | 2,269,407 | 60.2 | 3,825,595 | 51.6 |
| Cerebral Palsy | 270,524 | 8.4 | 245,036 | 6.5 | 607,943 | 8.2 |
| Epilepsy | 305,949 | 9.5 | 211,108 | 5.6 | 600,530 | 8.1 |
| Autism | 103,057 | 3.2 | 120,633 | 3.2 | 252,074 | 3.4 |
| Other | 421,887 | 13.1 | 923,595 | 24.5 | 2,127,802 | 28.7 |
| TOTAL | 3,220,519* | 100 | 3,769,779 | 100 | 7,413,944 | 100 |
| **Special Projects** | | | | | | |
| Mental Retardation | 11,984,586 | 70.4 | 8,164,079 | 65.3 | 2,685,141 | 56.5 |
| Cerebral Palsy | 1,395,915 | 8.2 | 1,189,821 | 9.5 | 587,761 | 12.3 |
| Epilepsy | 2,795,349 | 16.4 | 1,610,778 | 12.9 | 696,678 | 14.6 |
| Autism | 398,790 | 2.4 | 299,433 | 2.4 | 121,763 | 2.6 |
| Other | 444,793 | 2.6 | 1,238,808 | 9.9 | 664,657 | 14.0 |
| TOTAL | 17,019,433* | 100 | 12,502,919 | 100 | 4,756,000 | 100 |
| **University Affiliated Facilities** | | | | | | |
| Mental Retardation | 3,575,000 | 55.0 | 4,081,000 | 55.0 | 3,850,000 | 55.0 |
| Cerebral Palsy | 546,000 | 8.4 | 593,600 | 8.0 | 574,000 | 8.2 |
| Epilepsy | 416,000 | 6.4 | 415,520 | 5.6 | 420,000 | 6.0 |
| Autism | 208,000 | 3.2 | 237,440 | 3.2 | 238,000 | 3.4 |
| Other | 1,755,000 | 27.0 | 2,092,440 | 28.2 | 1,918,000 | 27.4 |
| TOTAL | 6,500,000 | 100 | 7,420,000 | 100 | 7,000,000 | 100 |

*Funds reprogrammed with Congressional approval.

3. Quality Assessment - Summary Observations

A primary concern of the Developmental Disabilities Program has been that developmentally disabled individuals receive needed services in humane environments, services which enable individuals with developmental disabilities to achieve their maximum potential.

There are several current efforts which relate to the assurance of quality services:

- Individualized Habilitation Plans: Each developmentally disabled individual who receives services through the Developmental Disabilities Program must have a plan developed which states long term goals and objectives and the services to be provided to achieve those goals;
- Protection and Advocacy System: A function of the system is to assure that needed services are delivered, that the services delivered meet minimum standards for quality, and that the services produce the desired changes;
- Professional and Paraprofessional Assessment: An instrument has been developed to assess the skills and qualifications of the various groups of professionals and paraprofessionals serving individuals with developmental disabilities;
- Comprehensive Evaluation System: This is to be a State operated client centered evaluation system designed to

evaluate services provided to developmentally disabled individuals on the basis of the degree of developmental progress attained by clients of these services.

- National Standards for Developmental Disabilities Services: These standards have been available and in use for some years and some programs also use the national compliance-assessment service offered by the developers of the standards, the Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons.

Each of these activities either takes place or will take place at the State or provider levels, where the main responsibility for assuring the delivery of quality services rests. Although the intensity of quality related activities has increased in the years following enactment of P. L. 95-602, few of these activities can be related directly to the change in the definition of developmental disabilities.

## Basic State Grant Program

The comprehensive State plans for services to individuals with developmental disabilities for fiscal years 1978, 1979, 1980 were reviewed for the data necessary to provide information on the Basic State Grant Program. The information gathered was returned to the States for verification and provided the main portion of the data included in the report entitled "The Impact of the Amendment of the Definition of 'Developmentally Disabled' on the Developmental Disabilities Program in FY 1979 and FY 1980."

The States reported their estimated developmental disabilities population by category of disability in fiscal year 1978 and most of the States continued to report their estimated population by the category of disability in fiscal year 1979. Only ten States, or 19 percent of the programs, reported their fiscal year 1980 estimated population by disability in their State Plans.

### Individuals Planned For

The following table shows the estimated developmental disabilities population by disability for each of the three fiscal years, based on data compiled from the plans developed by the State Planning Councils.

| Category of Disability | Fiscal '78 Number | % | Fiscal '79 Number | % | Fiscal '80[1] Number | % |
|---|---|---|---|---|---|---|
| Mental Retardation | 3,518,742 | 65.5 | 3,291,862 | 64.3 | 2,140,988 | 54.8 |
| Cerebral Palsy | 505,269 | 9.4 | 623,909 | 12.2 | 558,688 | 14.3 |
| Epilepsy | 1,064,479 | 21.8 | 1,007,646 | 19.7 | 679,802 | 17.4 |
| Autism | 79,866 | 1.5 | 75,431 | 1.5 | 62,510 | 1.6 |
| Other(2) | 97,490 | 1.8 | 120,011 | 2.3 | 464,925 | 11.9 |
| Total | 5,265,846 | 100 | 5,118,859 | 100 | 3,906,913 | 100 |

1 The numbers are extrapolated from the percentages provided by the ten States which provided categorical information in their fiscal year 1980 State Plans.

Ten States estimated in their fiscal year 1980 State Plans their developmental disabilities population identifying these four causes of disability: mental retardation, cerebral palsy, epilepsy, and autism. Seven States did utilize a fifth category of the cause of disability, the composition of which varied from State to State. Five of the States have some combination of multiple handicapping conditions in this category, while two States considered the population of learning disabled as a separate category.

It appears from an analysis of these data that States are focusing on the substantially handicapped to a greater extent in estimating the developmental disabilities population in fiscal year 1980 than when they estimated the developmental disabilities population in fiscal year 1978. Additionally,

the elimination of the mildly mentally retarded and the ability to control seizures in persons with epilepsy accounted for a substantial reduction in the number of individuals considered developmentally disabled.

A comparison of total estimated developmental disabilities population for fiscal years 1978, 1979, and 1980 by State is provided in Appendix D. These comparisons are based on the estimates of the statewide developmental disabilities population contained in the State Plans.

The table below reveals that individuals with conditions described in Public Law 94-103 comprised 88.2 percent of the developmental disabilities population in fiscal year 1980; 11.8 percent were newly eligible.

| Disability groups | FY '78 % | FY '79 % | FY '80 % |
|---|---|---|---|
| MR-CP-E-A | 98.4 | 95.8 | 88.2 |
| All Others | 1.6 | 4.2 | 11.8 |

Expenditures

The fact that the Basic State Grant monies are distributed according to population and size and the analysis of need in the Hill Burton formula is reflected in the distribution of the monies through the three fiscal years covered by this report. There was not a dramatic change in the percentage

received by the various States from the Basic State Grant Program with the exception of the shift caused by the increase to minimum allotment States in fiscal year 1979.

The following table contains the distribution of all Basic State Grant funds by disability group for FY '78, FY '79, and FY '80.

| Disability Group | Fiscal '78 | | Fiscal '79 | | Fiscal '80 | |
|---|---|---|---|---|---|---|
| | Amount | % | Amount | % | Amount | % |
| Mental Retardation | $21,290,812 | 70.8 | $23,877,602 | 67.6 | $26,363,863 | 61.1 |
| Cerebral Palsy | 2,673,606 | 8.9 | 4,389,011 | 12.4 | 5,283,336 | 12.2 |
| Epilepsy | 4,646,130 | 15.5 | 4,385,125 | 12.4 | 5,109,232 | 11.8 |
| Autism | 957,024 | 3.2 | 1,217,963 | 3.4 | 1,339,173 | 3.1 |
| Other | 490,428 | 1.6 | 1,461,299 | 4.2 | 5,084,396 | 11.8 |
| TOTAL | $30,058,000 | 100 | $35,331,000 | 100 | $43,180,000 | 100 |

Although there has been a decrease in the percentage of funds expended related to mental retardation, the amount of funds increased each year. In addition, the percentage expended related to mental retardation continues to be greater than the percentage of the total developmental disabilities populaion represented by mental retardation.

Generally, a similar trend is noted in the other categories of conditions. The exception is epilepsy for which consistently less funds have been expended as a percentage of total program funds expended for the developmental disabilities population. In addition, there was a slight decrease in the amount of funds expended for epilepsy in FY 1979. A factor which could explain this is that seizure disorders or epilepsy often accompany other conditions, such as mental retardation, and the primary diagnosis is a condition other than epilepsy. There is some question as to whether the population counts by category are discrete. Nonetheless, efforts are currently underway to analyze further this information related to epilepsy and to determine future courses of action.

The annual increase in funds expended for "other" categories of conditions indicates that States are expanding the target population beyond the previously named four conditions. It could be expected that the "other" category would continue to grow as experience with the use of the functional definition grows.

The table which follows contains a comparison of the percent of expenditures for each category of disability for the fiscal years under analysis. The data indicate changes have occurred in the amounts of funds expended for each category, changes which can be attributed generally to the change in the definition.

| Disability Group | Percent Expended in FY '78 | Percent Expended in FY '79 | Percent Expended in FY '80 |
|---|---|---|---|
| Mental Retardation | 70.8 | - 3.2 | - 9.7 |
| Cerebral Palsy | 8.9 | + 3.5 | + 3.3 |
| Epilepsy | 15.5 | - 3.1 | - 3.7 |
| Autism | 3.2 | + .2 | + .1 |
| Other | 1.6 | + 2.6 | +10.2 |

Assessment of Quality

Public Law 95-602 requires that "an assessment, evaluation and comparison of services provided to persons with developmental disabilities" be included in the mandated report.

It may be concluded that the quality of services provided with Basic State Grant funds to individuals with developmental disabilities remained constant or improved from the period of October 1, 1978 to September 30, 1980. There is nothing in the analysis of the project and program information which would indicate that the quality of service deteriorated during this period of time. The efforts of the State Planning Councils and their administering agencies in the area of standards and quality assurance have significantly increased between fiscal year 1978 and fiscal year 1980.

## Protection and Advocacy System

The legal and individual client advocacy and protection of the rights of developmentally disabled individuals is the function of the Protection and Advocacy System. The Protection and Advocacy System is outside of the service system and is supported with a grant in aid which is separate from the Developmental Disabilities Basic Grant Program allotment. Designated agencies receiving allotments for protection and advocacy of the rights of the developmentally disabled must be independent of any State agency which provides services to the developmental disabilities population.

The State Protection and Advocacy offices are characterized by a diversity of organizational structure. Among the key factors serving to differentiate offices are the nature of implementation, i.e. public, private, established by Executive Order, established by statute; nature of facilities (single site, multiple sites); philosophy of organization (emphasis on legal model or on advocacy model); staffing patterns (numbers and types of professional and paraprofessionals employed); and resources (State and agency funding).

Services provided by Protection and Advocacy offices include outreach, hotlines, information and referral, counseling and legal services, advocacy activities (individual, systems, and legislative) and training.

Individuals Served

The Protection and Advocacy System has been less oriented to the categorical concept than the Basic State Grant and the Special Projects. The definition contained in Public Law 95-602 appears to have influenced service to a broad target population by the Protection and Advocacy System.

The effect of the change has been an increase in the number of individuals, with conditions other than the four specified in the previous definition, receiving protection and advocacy services. However, the total number of individuals who are mentally retarded receiving protection and advocacy services did not significantly decreased in either fiscal year 1979 or fiscal year 1980.

The following table contains the number and percent of individuals served by Protection and Advocacy offices in fiscal year 1978, fiscal year 1979, and fiscal year 1980 by cause of disability.

| Category of Disability | Fiscal '78 Number | % | Fiscal '79 Number | % | Fiscal '80 Number | % |
|---|---|---|---|---|---|---|
| Mental Retardation | 9,542 | 65.8 | 16,265 | 60.2 | 14,073 | 51.6 |
| Cerebral Palsy | 1,218 | 8.4 | 1,756 | 6.5 | 2,236 | 8.2 |
| Epilepsy | 1,377 | 9.5 | 1,513 | 5.6 | 2,209 | 8.1 |
| Autism | 464 | 3.2 | 865 | 3.2 | 927 | 3.4 |
| Other | 1,900 | 13.1 | 6,619 | 24.5 | 7,828 | 28.7 |
| Total | 14,501 | 100 | 27,018 | 100 | 27,273 | 100 |

The increase of individuals with other handicaps who were served by Protection and Advocacy offices could originate from factors other than the change in the Federal definition of developmental diabilities. Sixteen States received State monies for the operation of the Protection and Advocacy program. Eligibility criteria for handicapped persons were changed in some States with the provision of State monies for protection and advocacy. The State contribution to protection and advocacy increased $1.2 million in fiscal year 1979 from fiscal year 1978. Some States required their Protection and Advocacy offices to serve all handicapped.

The number of individuals served by Protection and Advocacy offices in fiscal year 1980 was 27,273. Of this number, 51.6 percent of the individuals served were mentally retarded. There were 2,236 individuals with cerebral palsy served in fiscal year 1980, which represented 8.2 percent of the total clientele. Individuals with epilepsy represented 8.1 percent of the clientele, and 3.4 percent of those served were autistic individuals. The individuals in the category of 'other' served in fiscal year 1980 increased significantly.

The table below shows the changes in individuals served who were mentally retarded, cerebral palsied, epileptic, and autistic and all other individuals served by Protection and Advocacy agencies for fiscal year 1978, fiscal year 1979, and fiscal year 1980.

One could conclude from these data that the impact of the change in the definition of developmental disabilities in Public Law 95-602 was to shift the clientele of the protection and advocacy system approximately 15 percent from individuals with mental retardation, cerebral palsy, epilepsy or autism to individuals with other types of handicapping conditions. However, it is not known what part State requirements in those States which received State funds played in the shift of Protection and Advocacy clientele over fiscal year 1979 and fiscal year 1980. It can be concluded for the purposes of this report that the definition in Public Law 95-602 was the major factor in the shift of clientele.

| Category of Disability | FY '78 % | FY '79 % | FY '80 % |
|---|---|---|---|
| MR - CP - E - A | 86.9 | 75.5 | 71.3 |
| All Others | 13.1 | 24.5 | 28.7 |
| Total | 100 | 100 | 100 |

## Expenditures

The data compiled on expenditures for the Protection and Advocacy system reflect the percentage a particular category of disability is of the total developmental disabilities population served by the Protection and Advocacy system in a given fiscal year. The reporting system does not capture expenditures by category of condition. The table below distributes the expenditures by the categorical percentage of the total developmental disabilities population served by the Protection and Advocacy system in each of the three fiscal years.

| Category of Disability | Fiscal '78 Number | % | Fiscal '79 Number | % | Fiscal '8 Number | % |
|---|---|---|---|---|---|---|
| Mental Retardation | $2,119,102 | 65.8 | $2,269,407 | 60.2 | $3,825,595 | 51.6 |
| Cerebral Palsy | 270,524 | 8.4 | 245,036 | 6.5 | 607,943 | 8.2 |
| Epilepsy | 305,949 | 9.5 | 211,108 | 5.6 | 600,530 | 8.1 |
| Autism | 103,057 | 3.2 | 120,633 | 3.2 | 252,074 | 3.4 |
| Other | 421,887 | 13.1 | 923,595 | 24.5 | 2,127,802 | 28.7 |
| TOTAL | $3,220,519 | 100 | $3,769,779 | 100 | $7,413,944 | 100 |

In terms of expenditures, however, it should be remembered that the resources for protection and advocacy continued to grow from a $5.3 million program in fiscal year 1978 to a $12.6 million program in fiscal year 1981. Protection and Advocacy offices have consistently attracted 40 percent of their resources from alternative funding sources other than the grants received from Section 113 of Public Law 95-602.

The clientele of the Protection and Advocacy agencies is increasingly becoming those multiply handicapped individuals who have no specific service resource in the generic service system.

Assessment of Quality

A primary function of the Protection and Advocacy system is to assure the provision of quality services to individuals with developmental disabilities. The data do not indicate that the change in the definition of developmental disabilities had any measureable effect on the Protection and Advocacy offices as they carried out this responsibility.

## Special Projects

Special Projects grants are made to public or nonprofit organizations for demonstration projects establishing programs which hold promise of expanding or otherwise improving:

- Services to persons with developmental disabilities, especially those who are disadvantaged or multi-handicapped;
- Program linkages with other agency programs which impact on developmentally disabled individuals; and
- State capacities to enlarge personnel resources and enhance the knowledge and skills of all persons, professional and para-professionals, working with developmentally disabled persons in specialized or generic services.

### Individuals Served

The apparent effect of applying the functional definition of developmental disabilities on the number of individuals involved in Special Projects is a decrease in the percent of individuals with mental retardation by almost 25 percent, an increase in the other three previously named categories of conditions, and an increase of 11.1 percent in the number of individuals with 'other' handicapping conditions.

The table which follows contains a comparison of the percentage of individuals involved in Special Projects by disability for each of the three fiscal years. The percentage change is against the FY 1978 base year.

| Disability Group | FY '78 Percent of Disability Group | FY '79 Percent of Change | FY '80 Percent of Change |
|---|---|---|---|
| Mental Retardation | 79.0 | - 5.8 | - 24.9 |
| Cerebral Palsy | 3.3 | + .9 | + 10.4 |
| Epilepsy | 12.0 | + 3.7 | + 3.1 |
| Autism | 1.5 | + .4 | + .3 |
| Other | 4.2 | + .8 | + 11.1 |

Expenditures

The table below contains the expenditures for Special Projects by category of condition.

| Disability Group | FY '78 | | FY '79 | | FY '80 | |
|---|---|---|---|---|---|---|
| | Amount | % | Amount | % | Amount | % |
| Mental Retardation | $11,984,584 | 70.4 | $ 8,164,079 | 65.3 | $2,685,141 | 56.5 |
| Cerebral Palsy | 1,395,915 | 8.2 | 1,189,821 | 9.5 | 587,761 | 12.3 |
| Epilepsy | 2,795,349 | 16.4 | 1,610,778 | 12,9 | 696,678 | 14.6 |
| Autism | 398,790 | 2.4 | 299,433 | 2.4 | 121,763 | 2.6 |
| Other | 444,793 | 2.6 | 1,238,808 | 9.9 | 664,657 | 14.0 |
| Total | $17,019,433(1) | 100 | $12,502,919 | 100 | $4,756,000 | 100 |

(1) Does not include over $2 million spent for employment and vocational development.

The apparent effect of applying the definition of developmental disabilities in Public Law 95-602 in the Special Projects area is a 14 percent decrease in the percent of funds expended on projects for individuals with mental retardation, an increase in the percentage for the other three previously stated categories, and an 11 percent increase for individuals with 'other' handicapping conditions.

The following table indicates the changes in the Special Project funds expended on each category of condition for the three fiscal years being analyzed.

| Disability Group | FY '78 Percent | FY '79 Percent of change | FY '80 Percent of change |
|---|---|---|---|
| Mental Retardation | 70.4 | - 5.1 | - 13.9 |
| Cerebral Palsy | 8.2 | + 1.3 | + 4.1 |
| Epilepsy | 16.4 | + 3.5 | + 1.8 |
| Autism | 2.4 | 0 | + .2 |
| Other | 2.6 | + 7.3 | + 11.4 |

Assessment of Quality

The major effort, funded under the Special Project grant authority, related to quality has been the continued support provided to the Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons (ACMRDD) in their development and application of standards for services for the developmentally disabled population. Over half of the States are utilizing these standards. In addition, ACMRDD provides a national compliance-assessment service related to its standards. The greater acceptance and use of these standards for service provision over the past two years might indicate an increase in the quality of service, but this increase does not specifically relate to the change in the definition.

## University Affiliated Facilities Program

The University Affiliated Facilities (UAFs) form a national network of facilities in 35 States where children and adults, through high quality demonstration programs, are provided diagnostic and other services. UAFs are responsible for:

- Serving individuals with complex disabilities for which services are not otherwise available;
- Training professionals in their States and regions to promote proper diagnosis and treatment in statewide services; and
- Assisting State and local planning agencies to organize necessary services.

The Developmental Disabilities Program provides core grant funding to 36 of the 48 University Affiliated Facilities. Although this core grant funding amounts to less than 10 percent of the combined budgets for University Affiliated Facilities, this core grant funding allows the University Affiliated Facilities to cover basic expenditures and provides a base on which to build a program utilizing a wide variety of funding sources and programs. The developmental disabilities funds serve as a catalyst for securing other programmatic funds.

The combined annual budget of University Affiliated Facilities is in excess of $100 million. These funds are obtained from a variety of sources including the Administration on Developmental Disabilities, Maternal and Child Health, State general funds, Rehabilitation Services Administration, university general funds, fees for service, Public Health Service, and the Office of Special Education.

In addition, State Planning Councils, State governments, and State service providers use the resources of University Affiliated Facilities to provide direct client services, technical assistance, training, and research. State grants accounted for 28.4 percent of the funds received in grants by numerous University Affiliated Facilities for a total of almost $18.6 million including $760,000 received from State planning councils for training and research activities.

Local agencies, service providers, and organizations use the resources of University Affiliated Facilities for activities similar to those provided to State organizations. Grants from local organizations and agencies accounted for 8.4 percent of the grant monies received by University Affiliated Facilities.

Individuals Served

The following chart indicates the estimated number and percentage of individuals provided direct client services by twenty-one of the forty-eight UAFs reporting such data to the UAF data base. The data indicate that the change in the definition had little impact on the UAF program.

| Category of Disability | Fiscal '78 Number | % | Fiscal '79 Number | % | Fiscal '80 Number | % |
|---|---|---|---|---|---|---|
| Mental Retardation(1) | 12,455 | 55.0 | 12,924 | 55.0 | 13,475 | 55.0 |
| Cerebral Palsy | 1,902 | 8.4 | 1,880 | 8.0 | 2,009 | 8.2 |
| Epilepsy | 1,450 | 6.4 | 1,316 | 5.6 | 1,470 | 6.0 |
| Autism | 725 | 3.2 | 752 | 3.2 | 833 | 3.4 |
| Other(2) | 6,114 | 27.0 | 6,627 | 28.2 | 6,713 | 27.4 |
| Total | 22,646 | 100 | 23,499 | 100 | 24,500 | 100 |

1 Percent of individuals with mental retardation is based on the FY '79 experience and used for FY '78 and FY '80.

2 Includes individuals who are emotionally handicapped, physically handicapped, deaf, blind,learning disabled, and who have metabolic disorders or dyslexia.

Expenditures

The data presented in this report on expenditures for the UAF program reflect the relationship between each condition and the total developmental disabilities population served by the UAF program in a given fiscal year. The reporting system which provided data for the preparation of this report does not capture expenditures by condition. The following table, therefore, distributes the expenditures based on the percentages derived from the preceding chart on individuals with each condition who were served by the UAF program in each of the three years.

| Category of Disability | Fiscal '78 Number | % | Fiscal '79 Number | % | Fiscal '80 Number | % |
|---|---|---|---|---|---|---|
| Mental Retardation(1) | $3,575,000 | 55.0 | $4,081,000 | 55.0 | $3,850,000 | 55.0 |
| Cerebral Palsy | 546,000 | 8.4 | 593,600 | 8.0 | 574,000 | 8.2 |
| Epilepsy | 416,000 | 6.4 | 415,520 | 5.6 | 420,000 | 6.0 |
| Autism | 208,000 | 3.2 | 237,440 | 3.2 | 238,000 | 3.4 |
| Other(2) | 1,755,000 | 27.0 | 2,092,440 | 28.2 | 1,918,000 | 27.4 |
| Total | $6,500,000 | 100 | $7,420,000 | 100 | $7,000,000 | 100 |

1 Percent of individuals with mental retardation is based on the FY '79 experience and used for FY '78 and FY '80.

2 Includes individuals who are emotionally handicapped, physically handicapped, deaf, blind,learning disabled, and who have metabolic disorders or dyslexia.

Assessment of Quality

The University Affiliated Facilities are now operating under standards according to the mandate contained in the 1978 Amendments to the Developmental Disabilities and Bill of Rights Act.

With the promulgation of the standards for University Affiliated Facilities, the services at University Affiliated Facilities have become standardized. Most direct services provided by University Affiliated Facilities are governed by State and Federal rules and regulations. The study did not reveal any causal relationships, however, been the quality assurance efforts in the University Affiliated Facilities Program and the change in the definition.

## Part III: CONCLUSIONS

The major conclusions to evolve from this report on the impact of the change in the definition of developmental disabilities are presented below. The conclusions are based on the material in the preceding sections of this report.

1. <u>There has been a decrease in the developmental disabilities population.</u>

   The change from the categorical definition to a functional definition has resulted in a significant decrease in the population defined as individuals with developmental disabilities. The main changes within this population group have been the addition of new disability conditions and the decrease in mentally retarded individuals who are considered developmentally disabled. Some of these conditions which may be considered developmental disabilities, based on the functional limitations of individuals, are:

   Cystic fibrosis
   Deaf-blindness
   Osteogenesis imperfecta
   Socially impaired learning disabled
   Spina bifida
   Tourette's syndrome
   Tuberous sclerosis

2. The mental retardation portion of developmental disabilities population has decreased by ten percent.

Under the previous categorical definition, many States considered any mentally retarded individuals to be developmentally disabled, regardless of the degree of mental retardation or the substantially of the handicap. The functional definition, however, focuses on the more substantially handicapped portion of those individuals with mental retardation, thereby causing mildly mentally retarded individuals no longer to be considered developmentally disabled unless there are multiple handicaps which in combination substantially limit the individual's ability to function.

3. The use of the functional definition has resulted in an increase in the number of individuals with cerebral palsy considered developmentally disabled and a decrease in those with epilepsy and autism included within the developmental disabilities population.

There is a ten percent increase in the number of individuals with cerebral palsy considered to be developmentally disabled when the State plan figures for FY 1978 are compared with those for FY 1980. A comparison of the State plan epilepsy and autism estimates for the same two years reveals a decline in the number individuals in those two categories who are defined as developmentally disabled. Approximately one million individuals with epilepsy, or 22% of the developmentally disabled population,

were considered to be developmentally disabled in the FY 1978 State plans. In the FY 1980 State plans, the number of individuals with epilepsy in the developmental disabilities population was estimated to be 679,802. Individuals with epilepsy are estimated to be 17% of the total developmental disabilities population when the functional defintion is utilized.

Autism represented 1.5% of the developmental disabilities population in the FY 1978 State plans and 1.6% in the FY 1980 State plans. The number of individuals with autism considered to be developmentally disabled, however, decreased from approximately 80,000 individuals in FY 1978 to 62,500 individuals in FY 1980.

4. Individuals identified as developmentally disabled and having "other handicapping conditions" account for almost 12% of the total developmental disabilities population.

The FY 1980 State plans estimated that individuals with conditions other than the four conditions listed in the previous definition of developmental disabilities accounted for 11.9% of the developmental disabilities population. These 464,925 individuals have conditions such as spina bifida, tuberous sclerosis, or osteogenesis imperfecta. The dramatic increase within the developmental disabilities population in the number of individuals with handicapping conditions other than the four specified under the previous defintion is directly related to the change from categorical definition in P.L. 94-103 to the functional definition in P.L. 95-602.

5. The application of the functional definition seems to have resulted in the identification of more substantially handicapped individuals as developmentally disabled.

Although the previous definition also specified that the handicap be substantial, the definition was frequently misinterpreted too inclusively to include all individuals who fell into the four categories mentioned in the definition (mental retardation, cerebral palsy, epilepsy, and autism) regardless of the degree of disability. The functional definition has focused the efforts of the Developmental Disabilities Program on those individuals who are more substantially handicapped and who historically have been underserved or not served at all.

6. There was a six percent decrease in expenditures for mental retardation in the four program components between FY 1978 and FY 1980.

The reduction in the mental retardation expenditures can be related to the focus on severity of the condition in the functional definition. Generally, the mildly mentally retarded are no longer included in the developmentally disabled population unless there are multiple handicaps which in combination substantially limit the individual's ability to function. However, mental retardation continues to receive a higher percentage of

funds than the percentage which the condition represents of the total developmentally disabled population. Over one-half the expenditures in each program component in FY 1978 and FY 1980 were related to mental retardation.

7. Expenditures in the category cerebral palsy increased approximately 44 percent between FY 1978 and FY 1980.

   There seems to be no clear explanation for this change at this time.

8. There was a sixteen percent decrease in expenditures for the epilepsy category between FY 1978 and FY 1980.

   The epilepsy groups had been concerned when the functional definition was enacted that those individuals with epilepsy whose seizures could be controlled with drugs so that their limitations were minimal would no longer be defined as developmentally disabled. The decrease in expenditures may reflect the decrease noted in the number of individuals with epilepsy now considered to be developmentally disabled.

9. Expenditures for autism increased approximately 17 percent between FY 1978 and FY 1980.

   The study revealed no causal factors for this change.

10. The greatest increase in expenditures between FY 1978 and FY 1980 was in the category of other handicapping conditions.

The expenditures in this category quadrupled with the introduction of the functional definition, the main factor which caused the shift in expenditures.

11. Although the intensity of quality related activities has increased in the years following the enactment of P.L. 95-602, few of these activities can be related directly to the change in the definition of developmental disabilities.

The study did not reveal any causal relationships between the quality assurance efforts undertaken by the Developmental Disabilities Program and the change in the defintion.

The Developmental Disabilities Program has, from its inception, filled an important role in the total complex of Federal and State services for disabled individuals. Unlike most other programs, its primary purpose is not the direct delivery of large amounts of service. Rather, it is intended to serve as an advocacy force, planning, mobilizing, and coordinating existing resources so that they serve the target population more appropriately, effectively, and efficiently in the States. The target population of the program has always been that portion of the handicapped population which is least likely to receive adequate care from generic agencies or even from programs aimed specifically at handicapped individuals.

The Developmental Disabilities Program has had an involved and difficult role, whose impact is difficult to measure. It brought together consumer groups, State administering agencies, and private nonprofit providers of services in an effort to provide a comprehensive network of services for the developmental disabled population.

The need for the comprehensive network of services for this substantially handicapped population will continue to exist irrespective of the definition of developmental disabilities or the mode of funding of this network of services.

# APPENDIX A

## Historical Evolution of the Definition of Developmental Disabilities

The basic legislative action to which the 1978 Act is traced is the "Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963" (Public Law 88-164). Public Law 88-164 and its amendments are discussed below.

1. Public Law 88-164: The law provided Federal funds to: (1) build research centers for preventing and combating mental retardation; (2) construct public or non-profit clinical facilities (University Affiliated Facilities) which would provide inpatient/outpatient services, demonstrate how specialized services could be provided, and provide clinical training for physicians and others working with the mentally retarded; and (3) encourage States to build community facilities for the mentally retarded.

This was the first Federal categorical program for individuals with mental retardation, the only disability group specified in the legislation.

2. Public Law 90-170: The 1967 Amendments split the mental retardation and mental health components of the program and maintained the focus on persons with mental retardation.

3. Public Law 91-517: The 1970 amendments completely revamped the program in at least three ways. First, the target beneficiary group was broadened from persons with mental retardation to persons with "developmental disabilities." This was not merely a change or addition in label, presumably, since the term itself was new, but also a change in approach -- an emphasis on similar service needs rather than clinical categories. The target population included, in addition to mental retardation, disabilities of cerebral palsy, epilepsy, and other neurological conditions closely related to mental retardation. The term "developmental disability" was adopted to describe this new target group.

Second, it became a Federal/State partnership program involving extensive roles in decision-making at both the State and Federal levels.

And third, the purposes of the program became much more diversified. Rather than focusing exclusively on program assistance, the purposes were stated to include objectives like comprehensive State planning, models for innovative programming, demonstration and training grants — in short, capacity-building rather than the support of direct services, per se.

Mental retardation is, by definition, a disabling condition which begins early in life. It is a developmental disorder, interfering with normal development. There are, of course, a variety of other handicapping conditions experienced by children which interfere to some extent, either directly with their development or indirectly with their schooling and social experience as children. Not all of these handicapping conditions persist as substantial handicaps into adult life, however.

It had become apparent that the conditions which contribute to the disability of an adult and which are of early onset are quite different from those conditions experienced by adults who become disabled after they are adults. This fact was confirmed by the Social Security Administration in examining the disabilities of adults who are entitled to Social Security benefits because of the chronicity of their disability since childhood. The conditions identified by the Social Security Administration which contribute most to adult disabilities originating in childhood are mental retardation, cerebral palsy, epilepsy, autism, and various childhood psychoses.

When the term "developmental disabilities" was first introduced into Federal law, the mentally retarded were perceived as a major portion of a larger population whose substantial, continuing handicaps originating early in life necessitated a coordinated and ongoing programmatic approach without limitation by age, discipline, or service system. The individuals, whether as children or adults, would need special attention from health agencies, education agencies, agencies concerned with employment, dependency, housing, and social services. Thus, persons in this target group had a uniquely urgent need for interagency planning, coordination, and continuity. They also had a need for certain types of direct services which were very frequently unavailable in the communities in which they lived or even in the segregated residential institutions to which they were often sent.

4. Public Law 94-103: These Amendments expanded the target population to include autism as a fourth categorical condition and then added two other conditions:

The term "developmental disability" means a disability of a person which—

> "(A)(i) is attributable to mental retardation, cerebral palsy, epilepsy, or autism;
>
> "(ii) is attributable to any other condition of a person found to be closely related to mental retardation because such condition results in similar impairment of general intellectual functioning or adaptive behavior to that of mentally retarded persons or requires treatment and services similar to those required for such persons; or
>
> "(iii) is attributable to dyslexia resulting from a disability described in clause (i) or (ii) of this subparagraph;
>
> "(B) originates before such person attains age eighteen;
>
> "(C) has continued or can be expected to continue indefinitely; and
>
> "(D) constitutes a substantial handicap to such person's ability to function normally in society."

A few observations are offered about the second cluster. The condition had to be related to mental retardation and not to any of the other named conditions. The nature of the relationship to mental retardation need only encompass one of three possible links: similar impairment of general intellectual functioning, similar impairment of adaptive behavior, or need for similar treatment and services. One change from the 1970 Development Disabilities Act was that the other condition need not be neurological.

The third cluster of conditions which met the etiology restriction of the definition was dyslexia, but only when dyslexia resulted from mental retardation, cerebral palsy, epilepsy, autism, or conditions in the second cluster. Thus, the dyslexia category added little beyond emphasis to the overall scope of coverage.

This definition of developmental disabilities was intended to be inclusive of all individuals disabled by one or more of the four categories of disabilities who met certain criteria, e.g., who were disabled early in life and who were expected to remain disabled throughout their lives, and who were substantially handicapped. Unfortunately, perhaps because only four conditions were explicitly mentioned (along with dyslexia if it accompanied one of the other four conditions), the definition was frequently misinterpreted in ways which were simultaneously too <u>inclusive</u> and too <u>exclusive</u>. On the one hand, the definition had been interpreted to include all individuals who fell into the four categories mentioned in the definition (mental retardation, cerebral palsy, epilepsy, and autism) regardless of degree of disability. On the other hand, the definition had been interpreted as excluding all not fitting into these four conditions or categories. The specifics of this misinterpretation will be discussed later in this section.

In an effort to obtain an objective basis for reconciling the claims and counterclaims of different disciplinary and consumer interests concerning the definition of developmental disabilities, these Amendments called for a report to be made to Congress on the definition of developmental diability. Section 301(b) of the Act stipulated that:

> "The Secretary shall contract for the conduct of an independent objective study to determine (A) if the basis of the definition of the developmental disabilities (as amended by Title I of this Act) with respect to which assistance is authorized under such title is appropriate and, to the extent that it is not, to determine an appropriate basis for determining which disabilities should be included and which disabilities should be excluded from the definition, and (B) the nature and adequacy of the services provided under other Federal programs for persons with disabilities not included in such definition."

To this end, the Developmental Disabilities Office of the Department of Health, Education, and Welfare awarded a contract in September 1976 to Abt Associates, Inc. of Cambridge, Massachusetts. To carry out the extremely complex job of arriving at the "appropriate basis" for a definition of developmental disabilities, a National Task Force on the Definition of Developmental Disabilities was selected to ensure as broad a representation of perspectives, experiences, knowledge, and geographic locations as possible. The Task Force had the responsibility and authority to make the final recommendations submitted to the Congress and to the Secretary of Health, Education, and Welfare.

The Task Force proposed a noncategorical definition which placed emphasis upon the criteria of chronicity, early onset, multiple impairment, and need for ongoing services involving a multiplicity of service providers.

In order to emphasize the complexity, pervasiveness, and "substantiality" of the disabling conditions to be addressed by the Developmental Disabilities Program, the Task Force proposed that persons who were to be considered as part of the primary target group of the program would be impaired in at least three major life activities among seven enumerated. The result of the Task Force's efforts is the definition of developmental disabilities contained in Public Law 95-602 and quoted later in this section.

Programmatic changes, other than the definition, which were enacted with Public Law 94-103 included two new programs to benefit developmentally disabled persons: a system to protect and advocate for the rights of persons with developmental disabilities and a special project authority for at least twenty-five percent (25%) of each year's appropriation for projects of national significance.

5. Public Law 95-602: The Title V Amendments included:

- A redefinition of the developmentally disabled population to focus on the substantially handicapped based on a definition which emphasized substantiality and chronicity established by functional limitations;
- A shift of emphasis from comprehensive planning to priority service areas;
- A clarification in the role and an increase in consumer membership of the State Planning Councils;
- A clearer statutory delineation of the mission of university affiliated facilities; and
- Increased authorization levels for State protection and advocacy systems.

The definition of developmental disabilities, as contained in Public Law 95-602, the "Developmental Disabilities Assistance and Bill of Rights Act", Section 102(7), is:

> "(7) The term 'developmental disability' means a severe, chronic disability of a person which--
>
> (A) is attributable to a mental or physical impairment or combination of mental and physical impairments;
>
> (B) is manifested before the person attains the age twenty-two;
>
> (C) is likely to continue indefinitely;
>
> (D) results in substantial functional limitations in three or more of the following areas of major life activity: (i) self-care, (ii) receptive and expressive language, (iii) learning, (iv) mobility, (v) self-direction, (vi) capacity for independent living, and (vii) economic sufficiency; and
>
> (E) reflects the person's need for a combination and sequence of special interdisciplinary, or generic care, treatment, or other services which are of life-long or extended duration and are individually planned and coordinated."

The definition of developmental disability contained in Public Law 95-602, sometimes referred to as the new definition of developmental disability, is based solely on an individual's functional limitations, rather than the diagnosis or nature of his or her disabling condition. The definition of developmental disability contained in Public Law 94-103, the one used by the Developmental Disabilities Program until November 1978, generally applied to persons with one of the four handicapping conditions listed: mental retardation, cerebral palsy, epilepsy or autism.

The concept of substantiality of the handicap which results from a developmental disability can be conveyed in a number of ways. The previous definition referred to "a disability of a person which...constitutes a substantial handicap to such person's ability to function normally in society." The recommendations from the National Task Force and the Public Law 95-602 definition further explicated this concept by specifying some of the main aspects of functioning in society. The Public Law 95-602 definition conveys the concept of substantiality by indicating that an individual must be limited in more than one area of life functioning; and that the limitation in each of these areas must be extensive. Both the previous definition and the new definition make it clear that the impact of the developmental disability on the person is <u>pervasive</u> in that it has direct ramifications for the person's ability to function in society, not just a substantial limitation in one aspect of life.

APPENDIX B

Summary of Key Findings on the Developmentally Disabled Population in the United States

The key findings of the analysis are:

- There were a total of approximately 2.5 million non-institutionalized developmentally disabled individuals over age three in the United States in 1976 who comprised about 1.2% of the total population:

| | | |
|---|---|---|
| DD Population | 2,487,000 | 1.23% |
| Non DD Disabled Population | 26,578,000 | 13.13% |
| Total Disabled Population | 29,065,000 | 14.36% |
| Non Disabled Population | 173,368,000 | 85.65% |
| Total Non-Institutionalized Population | 202,433,000 | 100.00% |

- The developmentally disabled population comprises 8.5% of the over 29,000,000 disabled people in the United States.
- Of the total developmental disabilities population, about 35% is mentally retarded, 10% is seriously emotionally disturbed, 17% is sensory impaired, and the remaining 38% is physically impaired.

| | | |
|---|---|---|
| DD MR Population | 870,000 | 35.0% |
| DD seriously emotionally disturbed population | 259,000 | 10.42% |
| DD sensory impaired | 427,000 | 17.17% |
| DD physically impaired | 931,000 | 34.44% |
| Total DD Population | 2,487,000 | 100.00% |

- Over half the developmental disabilities population is under age eighteen, compared with the total population of which only about 30% is under age eighteen.
- A higher proportion of Blacks and Native Americans are reported to be developmentally disabled than are other ethnic/racial groups. More Blacks are reported to be mentally retarded or developmentally disabled physically impaired and more Native Americans are reported to be mentally retarded or developmentally disabled sensory impaired.
- About 25% of the developmentally disabled individuals come from families that are below the poverty level, compared to only about 19% for the non-developmentally disabled population and 11% for the non-disabled population. This was true quite consistently for sub-groups within the developmental disabilities population.
- Over three quarters of the total developmental disabilities population over age 18 has had no previous work experience, compared with less than one quarter of the remainder of the population.

- The annual income in 1975 of the developmental disabilities population is about one quarter the average of the non-disabled population, and about one third of the income of non-developmentally disabled persons. While non-disabled persons receive only about 1% of their total income from public assistance, and non-developmentally disabled persons receive about 14%, developmentally disabled individuals receive about 67% from public assistance. Conversely, developmentally disabled individuals receive less than 20% of their income from earnings compared to 65% for other disabled persons and 92% for non-disabled persons. Social security benefits are received by the largest number of developmentally disabled individuals compared to other sources of public assistance.
- The proportion of a state's population that is developmentally disabled varies from a low of .6% in Alaska to a high of 2.04% in West Virginia. The States that reported .90% or less of their total population to be developmentally disabled were:

| | |
|---|---|
| Alaska | Oregon |
| Colorado | Utah |
| Nevada | Wyoming |
| North Dakota | |

- The States that reported having 1.5% or more of their total population to be developmentally disabled were:

| | |
|---|---|
| Alabama | Mississippi |
| Arkansas | Tennessee |
| Georgia | West Virginia |
| Louisiana | |

# APPENDIX C

## Primary Resource Documents

1. The Impact of the Amendment of the Definition of "Developmentally Disabled" on the DD Program in FY '79 and FY '80 (December 1980): This report was the major resource used for the data contained in this report on the clients, services, and expenditures of the Developmental Disabilities Program components. The report was written and produced by the Institute for Comprehensive Planning under a contract with the Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons (AC/MRDD).

2. A Study of the Potential Impact of the Definition Recommended by the National Task Force on the Definition of Developmental Disabilities (September 1978-January 1981): A contract was awarded in September 1978 to Morgan Management Systems, Inc. to study the potential impact of a functional definition of developmental disabilities. After the passage of the functional definition in November 1978, however, the study focused instead on the ability of the program components to use the definition and on tools which might aid in utilizing

the functional definition. The study products, listed below, were completed by Gollay and Associates, Inc.:

- Estimates of the Size and Characteristics of the Non-Institutionalized Developmentally Disabled Population in the United States Based Primarily on an Analysis of the 1976 Survey of Income and Education;
- Operational Definition of Developmental Disabilities;
- Description of Major New Categories of Disabilities; and
- Summary Final Report.

3. Secretary's Report to Congress on the Definition of Developmental Disabilities (1978): This Report was mandated in Public Law 94-103, Section 301, to be submitted annually to the Congress. The Act required an annual report on the conditions which the Secretary had determined should be included and not included under the statutory definition of developmental disabilities. This Report recommended retention of the definition stated in Public Law 94-103.

4. Final Report of the Special Study on The Definition of Developmental Disabilities (November 1977): This was the report of the National Task Force on the Definition of Developmental Disabilities described earlier. In addition to the Final Report, several of the background papers prepared for the Task Force by the contractor's staff were used as resource documents.

# APPENDIX D

Estimated Developmentally Disabled Population Obtained From the Developmental Disabilities State Plans

| Regions/States | Estimated DD population for Fiscal Year '78 | Estimated DD population for Fiscal Year '80 | Percent of increase/ decrease from FY '78 |
|---|---|---|---|
| Region I | 190,289 | 165,960 | - 13 |
| Connecticut | 19,772 | 38,200 | + 93 |
| Maine | 43,792 | 16,587 | - 62 |
| Massachusetts | 93,210 | 80,474 | - 14 |
| New Hampshire | 5,974 | 12,542 | + 110 |
| Rhode Island | 6,115 | 9,957 | + 63 |
| Vermont | 21,426 | 8,200 | - 62 |
| Region II | 409,541 | 347,790 | - 15 |
| New Jersey | 125,855 | 116,670 | - 7 |
| New York | 125,980 | 70,520 | - 44 |
| Puerto Rico | 156,583 | 156,492 | 0 |
| Virgin Islands | 1,123 | 4,108 | + 266 |
| Region III | 510,276 | 429,689 | - 16 |
| Delaware | 30,760 | 16,660 | - 46 |
| Dist. of Columbia | 12,033 | 11,390 | - 5 |
| Maryland | 23,510 | 69,317 | + 195 |
| Pennsylvania | 318,919 | 164,519 | - 48 |
| Virginia | 104,990 | 156,500 | + 49 |
| West Virginia | 20,064 | 11,303 | - 44 |
| Region IV | 1,180,261 | 608,310 | - 48 |
| Alabama | 132,996 | 52,695 | - 60 |
| Florida | 240,457 | 118,793 | - 51 |
| Georgia | 153,707 | 102,380 | - 33 |
| Kentucky | 128,470 | 61,137 | - 52 |
| Mississippi | 57,399 | 33,633 | - 41 |
| North Carolina | 197,686 | 126,000 | - 36 |
| South Carolina | 110,579 | 23,299 | - 79 |
| Tennessee | 158,967 | 90,373 | - 43 |

| Regions/States | Estimated DD population for Fiscal Year '78 | Estimated DD population for Fiscal Year '80 | Percent of increase/ decrease from FY '78 |
|---|---|---|---|
| Region V | 926,064 | 751,464 | - 19 |
| Illinois | 190,581 | 192,272 | 0 |
| Indiana | 46,292 | 70,814 | + 53 |
| Michigan | 206,060 | 148,512 | - 28 |
| Minnesota | 95,015 | 98,739 | + 4 |
| Ohio | 298,701 | 157,706 | - 47 |
| Wisconsin | 89,415 | 83,421 | - 7 |
| Region VI | 844,648 | 488,364 | - 42 |
| Arkansas | 112,364 | 45,880 | - 59 |
| Louisiana | 43,040 | 43,884 | 0 |
| New Mexico | 17,275 | 20,300 | + 18 |
| Oklahoma | 156,806 | 159,723 | + 2 |
| Texas | 515,156 | 218,577 | - 58 |
| Region VII | 395,693 | 508,889 | + 29 |
| Iowa | 47,939 | 45,598 | - 5 |
| Kansas | 89,533 | 105,458 | + 18 |
| Missouri | 252,088 | 333,000 | + 32 |
| Nebraska | 6,133 | 24,833 | + 305 |
| Region VIII | 96,691 | 81,012 | - 16 |
| Colorado | 48,203 | 28,269 | - 41 |
| Montana | 7,560 | 12,403 | + 64 |
| North Dakota | 7,173 | 7,173 | 0 |
| South Dakota | 12,071 | 8,520 | - 29 |
| Utah | 13,272 | 22,599 | + 70 |
| Wyoming | 8,412 | 2,048 | - 76 |

| Regions/States | Estimated DD population for Fiscal Year '78 | Estimated DD population for Fiscal Year '80 | Percent of increase/ decrease from FY '78 |
|---|---|---|---|
| Region IX | 601,076 | 422,980 | - 30 |
| Arizona | 98,404 | 40,479 | - 59 |
| California | 476,100 | 359,854 | - 24 |
| Guam | 295 | 2,956 | + 902 |
| Hawaii | 12,711 | 10,637 | - 16 |
| Nevada | 13,566 | 9,054 | - 33 |
| Region X | 111,355 | 102,455 | - 8 |
| Alaska | 7,288 | 7,378 | 0 |
| Idaho | 35,368 | 15,453 | - 56 |
| Oregon | 8,905 | 24,720 | + 178 |
| Washington | 59,794 | 54,894 | - 8 |
| TOTAL | 5,265,894 | 3,906,913 | - 26 |